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ABSTRACT

The second report on the Canadian Welfare Council's study of the social and psychological aspects of mental handicaps in the population of Prince Edward Island reviews the development of the project, describes its current status, and outlines plans for continuation . The purpose of the study is to define the nature and prevalence of mental handicaps and thereby obtain valuable data for more adequate social planning and treatment for the mentally handicapped. Discussed are the development of the project to May 1968, details of the May to August operations (development of methodology, pilot study, construction of interview schedule, hiring and training the interview team, field work, data analysis), the present status as of September 1, 1968, and future plans. (KW)

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# MENTAL RETARDATION IN A CANADIAN PROVINCE:

## Pilot Study and Design Development, to September, 1968

Report No. 2

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September, 1968

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Report No. 2

This project is supported under Welfare Research Project 566-33-3, National Welfare Grants Program, Department of National Health and Welfare, Canada.

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U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
OFFICE OF EDUCATION

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## PREFACE

This is the second report on the Canadian Welfare Council's study of Mental Retardation in a Canadian Province. The first report outlined the basic elements of the proposed study design and was based on the original submission to the Department of National Health and Welfare.

The present document is a progress report on the initial steps of the research design development. It is issued as one of an anticipated series of brief reports that will record the development and progress of the study.

We would like to acknowledge the assistance of a number of individuals in the development of the project to date. While assistance and consultation are deeply appreciated, final decisions were made by the study directors and responsibility rests with them. The active involvement of Dr. M.N. Beck, Director of Mental Health, Province of Prince Edward Island, has been of major value. Discussions with Dr. Joseph F. Jastak regarding his work at the University of Delaware has been influential in the design development. Consultation with Dr. James Wanklin, School of Medicine, Dalhousie University, clarified a number of technical points and other issues relating to the Maritime region of Canada. Mr. Bryson MacDonald, Executive Director, Ottawa and District Association for the Mentally Retarded, assisted with the arrangements for training of interviewers. Mention must also be made of the several member families of the Association who served as subjects for the training sessions.

The co-operation of the populations of the two villages used in the pilot study was, of course, a mainstay of the work. Nor should we omit mention of the valued support (financial and otherwise) of the Department of National Health and Welfare, and of the Canadian Welfare Council staff. Much is, of course, owed to the patience and efficiency of our secretarial staff.

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# Mental Retardation in a Canadian Province:

## Report Number 2

The purpose of this report is fourfold: to review the development of the project to May 1968; to document in greater detail developments from May to August 1968, inclusive; to describe the status of the work as of September 1, and to outline plans for continuation to December 1968 and beyond.

## I Development of the Project to May 1, 1968

The study had its beginnings in October, 1967 when one of the study directors was on an extensive tour of Canada. The trip brought him into contact with several professional people at the provincial and local level, who were daily confronted with the problems of mental retardation. These problems frequently centered upon the social and psychological effects of the retardation rather than upon its medical aspects. Discussions resulting from those situations brought into focus the potential value of a study on the social and psychological aspects of mental retardation in a Canadian population. Little work had been done in this area either in Canada or abroad.

The available literature pointed out that a number of studies of retardation had been carried out under severely restrictive circumstances (military occupation (1) for example) and that many had populations restricted primarily to clinic or to hospital patients.

Data for other studies were dependent upon existing admission or case study records. A more rigorously controlled study based on the population of a specified geographical area would yield valuable data for social planning.

On the basis of the foregoing discussions and previous experience in the field of atypical children, the director outlined a feasibility study (19). The document was a request for funds to develop a research design for a study which would define the nature and prevalence of mental retardation in a Canadian population and, it was hoped, lead to more adequate social planning and treatment for mentally retarded individuals. The submission was made in December 1967, with approval forthcoming in February 1968. The main elements of the study drew heavily upon the work of Jastak (17) as has been reported previously (19).

The remainder of this period was spent in preliminary work on the design and particularly in the consideration of sampling procedures.* This was also the period of negotiation for suitable staff. During early March, a potential co-director ** for the study was brought to Ottawa and plans were finalized for her joining the project full time at the end of the university year. It was at this time that the first note on the development of methodology was written.***

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* Douglas Harland, research assistant, C.W.C., assisted in doing this work.

** Dr. Dorcas Butt, research psychologist. Assistant Professor, Department of Psychology, University of British Columbia.

*** In this report, several research notes will be referred to which are not for circulation but which are available in CWC files.

The location of the project had already been determined and previously reported (19,20). For further information on the decision to locate the major part of the project on Prince Edward Island, the reader is referred to Beck (2), Osberg (18), Sim (21) and Stokes (22). It may be noted that the methodology and instrumentation being developed can and should be given application in other areas of Canada.

## II May 1 to August 30, 1968

The research psychologist began working in Ottawa as co-director of the study on May 6 and was the first full time person employed. Since much of the initial period was devoted to the development of theory and method backing the study, no consideration was given to further staff. The two most pressing issues at this time were, first, the construction of instruments to be used to identify cases of mental retardation, and second, the development of a sampling procedure to be used in the study proper anticipated for 1969.

Consideration of these issues resulted in three research notes (6,7 and 8) in which the theoretical and methodological problems surrounding the study were discussed. A brief summary of the progress resulting from these research notes follows under the headings: definition of mental retardation, instrumentation, and the need for a pilot project.

### A) Development of Methodology

#### I Definition of Mental Retardation

Before selecting and constructing the research instrument, it was essential to describe theoretically what construct was to be measured.

There are many facets of retardation and previous researchers and writers have defined the construct differently. Thus, results and conclusions of studies are not strictly comparable. For example, mental retardation may be defined medically (in terms of diagnostic classification), psychometrically (in terms of psychological test performance), historically (on the basis of school, employment and other available records in the absence of the individual concerned) and socially (in terms of adequacy of performance in a social group). The present study is most concerned with intellectual and social retardation and as a result many types of impairment are of key importance. Physical, genetic, emotional and social impairments of an individual can all lead to the definition of retardation upon which the study will focus.

II Instrumentation

The instruments to be constructed would reflect the definition of mental retardation adopted in the study. Because the emphasis is upon intellectual and social retardation, the measurements selected include a variety of psychological scales and questions directed at the adaptive behaviour of the individual in his social and psychological environments. Instrumentation will be discussed further in a subsequent section of this report.

III The Pilot Study Rationale

After consideration of the two topics above and consideration of possible sampling procedures, the necessity of a pilot study became even more apparent.

There is a limit to the planning and projection that can be carried on from an office chair. Furthermore, it became increasingly evident that the pilot project should be carried out in Prince Edward Island, where it is expected the study proper will be initiated in 1969. Too many studies have miscarried in the field because procedures have not been critically pre-examined for weaknesses and in an appropriate test area.

Three pressing issues then came into focus. The first was to test the theoretical stand which had been taken. The second was to evaluate the instruments in terms of psychometric and theoretical adequacy and the third issue was to test and develop practical field procedures. It was assumed that a pilot study carried out in Prince Edward Island would answer all three basic issues.

B) The Pilot Study

Following the decision to conduct the pilot study in Prince Edward Island, a number of further plans were formulated. Briefly, the plans called for the interviewing and psychological testing of the total population of two small villages of different ethnic origin. It was intended that one of the villages would be Acadian French with a number of bilingual families and the other would be English speaking. A number of circumstances influenced these decisions. Bilingualism, for example, is a variable of major importance in Canada. It has been linked, in scientific literature, to certain types of retardation because exposure to and acquisition of two languages complicates the child's cognitive development.

A number of villages, thought to fall within these terms of reference, were outlined in a research note (8).

The final selection of villages was made during a planning visit to the Island by the study directors. Two villages in Prince County with populations of 268 and 330 were chosen with the help of study consultant, Dr. M.N. Beck. In addition to helping select the villages on the basis of his knowledge of and familiarity with Prince Edward Island, Dr. Beck arranged for the introduction of the principal investigators to key people in the villages. During the three-day trip, plans and arrangements were made for the pilot study. In three weeks a research team would return to carry out the interviewing and psychological testing in each of the villages.

C) Construction of the Interview Schedule

A number of problems had to be resolved before the final interview schedule could take shape. For example, the administration of a Wechsler intelligence scale requires highly trained personnel - preferably a clinical psychologist or practiced psychometrician. Such personnel could hardly be gathered together within the required time period. On the other hand, would there be enough time to transform the available interviewers into competent psychometricians? The latter was attempted.

The original plan was to simplify the administration of intelligence scales to make them easily manageable by university graduates or their equivalent. However, an attempt to follow through with this ran into impossible barricades due to copyright legalities.

Consequently the effort was abandoned in favour of training available interviewers to administer what is, in effect, a battery of tests.

The final interview schedule included the following sections.

1. Family History Form

This is a six-page booklet of items administered to the mother or mother substitute in each home. The booklet contains a series of questions: identifying the people living in the dwelling; determining the ethnic background of the family and language spoken in the home, and listing the handicapped individuals. In addition, it contains a social performance scale, in which the mother (or mother substitute) rates the level of performance of all children under five years of age and/or suspected mental retardates. For backgroundmaterial on the Social Performance Scale the reader is referred to Doll (12).

2. Individual Test Battery

This is an eighteen-page booklet for each individual's responses to the following tests and scales:

(i) Wechsler Intelligence Scale for Children

Four subtests from the Wechsler Intelligence Scale for Children: comprehension, similarities, picture completion and picture arrangement. These tests were individually administered to each subject (five years of age and older) in order to determine the level of intellectual

performance relative to other members of the village of the same age level. The Wechsler Intelligence Scale for Adults was considered for use in the study but later dismissed as being too difficult. The Wechsler-Bellevue, Forms I and II, was also considered.

(ii) Draw a Man or Draw a Person Test

This scale has long been used as an indication of children's levels of intellectual functioning. In it the child is simply asked to draw a picture of a person. The drawing is subsequently scored on the basis of the child's knowledge of the human figure and his ability to represent that knowledge in his drawing. The instrument is well documented in psychological literature and its use fully described by both Goodenough (14) and Harris (16).

(iii) Affect Scale

Bradburn's (2) short scales of positive and negative affect were included. They have had wide use as survey instruments which assess the feeling tone or level of happiness at which an individual is functioning. Ten questions are posed, five directed at the happy feelings an individual has experienced recently and five directed at the unhappy feelings he has experienced. Positive and negative affect have been found to be independent dimensions of feeling tone, each within their own set of external correlates.

(iv) Life History Information

This is a series of 32 questions which include factual, attitudinal and historical items. Some of the questions combine into single indices (such as socio-economic status). The items were written especially for this interview form, or were adapted from Glennon and Albright (13). They include items on a variety of content areas such as age, physical health, experience with reading materials, and personal attitudes towards the care of the disabled.

(v) Verbal Hostility Scale

This is a short scale from the Buss and Durkee (4) battery which assesses one aspect of the expression or aggression through verbal argument. The scale is included in view of the recent resurgence of interest in the expression of aggression as related to all areas of social adjustment.

(vi) Socialization Scale

This is a short adaptation of the Gough and Peterson (15)socialization scale which measures the degree to which an individual has internalized common social values. The scale is included as an assessment of how closely a person feels involved in the predominant social structure.

(vii) Personal Reaction Survey

This is a series of six questions directed at the individual's feelings and reactions to being interviewed. It is included as an indication of the co-operation of subjects and is therefore of methodological rather than theoretical importance.

D) Hiring the Interview Team

The selecting of individuals for field work posed several problems. Well-trained individuals in the behavioural sciences were required, preferably with backgrounds in psychological testing and previous field work experience. However, personal qualities were as important as technical ones. The team members would be required to enter the villages and establish immediate rapport with the people. Osberg (18) has noted in his paper:

> The positive factors that make the Island an interesting locus for research, offer collateral risks particularly for junior and inexperienced workers. If there are few secrets among those who are being studied, those doing the study will find they are also subject to unblinking scrutiny. For a skillful field man the Island would lend itself to fruitful and exciting exploration but it is no place for tinkering and manipulation. The centres of power are extremely close to the living context of life. A maladroit field worker would be given short shrift in P.E.I. no matter how impeccable his mainland sponsorship.

It was with these considerations that interviews with potential candidates were carried out. Finally, five individuals were hired for the month of field work planned in PEI.

| | Degree | Major Subject(s) | Age | Sex |
|---|---|---|---|---|
| 1. | BA, MA | Sociology | 25 | M |
| 2. | BA | Arts (Sociology) | 27 | M |
| 3. | BA | Arts (English & Psychology) | 21 | F |
| 4. | BA | Psychology | 25 | F |
| 5. | BA,B. Journalism | Arts (English & History) Journalism | 26 | F |

These individuals were in interim periods between jobs or on summer holidays. Their previous experiences ranged from social public health nursing through university teaching and previous interviewing in survey type research.

E) Training of Interviewers

A three-day schedule of intensive training was carried out from June 26 to 28. Details of the training are dealt with in "Training Schedule: Mental Retardation Research Group" (9). It included: instruction and discussion on the use of instruments, demonstration of the instruments at CWC and in the homes of Ottawa families having mentally retarded children. Training also included a visit to the Training School of the Ottawa and District Association for Mentally Retarded Children.*

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* The training sessions were arranged with the assistance of Mr.Bryson MacDonald, Executive Director, Ottawa and District Association for the Mentally Retarded.

A short reading list of required and recommended reading (10) was also part of the training procedure.

F) Field Work

Field work was carried out in the two villages from July 2 to 31. During the initial period one of the senior investigators remained in the field and for the last three days only two interviewers remained for the purpose of completing a few unfinished interviews.

The month of field work was extremely valuable for planning the 1969 phase of the study. Not only did it provide a wealth of information on the practical problems which must be overcome in the field, it also provided a useful set of data which is now being analyzed and interpreted. Some of the important issues raised and/or answered by the field work are covered under the following separate headings.

1) Transportation

Transportation for the research team members to and from the Island and in the field should be planned for well in advance and be liberally supplied. Three cars among five interviewers were not sufficient. Consideration should be given to individual transportation for each interviewer. One car between two field workers is only practical when the interviewers are living together and working in the same village. The use of personal cars by research team members is not a satisfactory arrangement.

2) Accomodation

Living arrangements for team members should also be made well in advance. It is difficult to find suitable accommodations anywhere on Prince Edward Island during the summer and even more difficult when a particular locality is required.

3) Time of Interviews

People living in the pilot project villages were quite amenable to being studied in the summer. However, the tourist season is so highly organized and overwhelming on some parts of the Island, that the summer cannot be considered a suitable time for interviewing. Week-ends, holidays, and festival times are not practical. Although Saturday morning is sometimes a satisfactory time for interviewing, families are often occupied with weddings or other special functions. On the basis of the pilot study experience it may be concluded that the afternoons and evenings of week days are the best times for interviewing.

4) Interviewer Morale

Care should be taken to make arrangements so that team members are kept in good spirits. Stresses inevitably arise when people are working closely together, and these should be watched at all times. An unhappy interviewer who does not feel enthusiastic and enjoy his work will not gather good data.

Some ways in which morale may be kept high are:

1. Send people in pairs in PEI (husband-wife teams, or people who are already good friends).
2. Supply strong on-the-spot leadership at all times.
3. Develop team spirit and/or competition over the job to be done.
4. Carry out all necessary introductions and arrangements for interviewers so the interviewers feel "expected" on the Island.
5. Have appointments set up in advance, perhaps by the senior personnel or the regular interviewers. In many ways, it is best if the interviewer makes his own appointments and is known to the family before he arrives to carry out the interview.

5) Personality of Interviewer

Some individuals, because of personal characteristics, do not make good interviewers. These characteristics will be spelled out at a later date and future personnel will be selected accordingly. Briefly, "role players" or persons hiding behind a "social front" are quickly detected and distrusted by rural people. This has particular relevance to Island people as Osberg aptly points out.*

6) Rapport

Rapport as an interview variable relates closely to the personality of the interviewer, as discussed in 5.

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* see quotation on page ~~11~~ 10 of this report.

Rapport must be established before the interview or the data will not be accurate. A person may be highly trained technically yet be incapable of establishing the simple trust necessary from his subject. Interviewers must be relatively free of hampering personal defences and possess good "ego strength".

7) Testing Conditions

Mobile vans should be considered in order to achieve more systematic control of the testing situation.

8) Contamination

After interviewing teams have worked in a village for a month, questions and answers are fully discussed by the people who have participated in spite of requests that this not be done. On one occasion during the pilot study a mother announced to an interviewer that the whole family was expecting her, and the children had been practising drawing people all morning.

9) Presentation of the Study to Subjects

The solution to this problem seems to be the function of the interviewer's personality. However, the direct and unaffected approach should be used.

10) Field Supervision

The research team in the pilot project was left with little supervision after the first week of interviews. During the first week, supervision was lenient. This situation was due to time pressures, other administrative work and pure fatigue on the part of the supervising psychologist.

However, in the study proper a supportive and critical supervisor should be close to the interviewers at all times. The position of field supervisor would ideally be an older individual with a master's degree in clinical psychology and several years clinical experience or an experienced field supervisor in social research of this nature.

11) Refusals

The rate of participation by the villagers in the study was so high that little was learned about how to deal with outright refusals. Of the 2.65 per cent who did refuse, the main factor seemed to be a deeply engrained personality trait due to illness, extreme suspicion, or pure negativism that interfered with the individual's social identification. If the person had little feeling of attachment to or involvement with the village and others; there was little to motivate co-operation. In fact, refusal to participate would strengthen and justify the self-concept of isolation and suspicion. It should be noted, however; that in one case such a person was capable of influencing a handful of others to the decision not to participate.

G. Data Analysis and Background Work in Ottawa

1. Suitability of the Interview Form

After item analysis of the data it will be possible to exclude questions and scales from the interview form which are unworkable in a Prince Edward Island population. It is probably inevitable that the interview form is highly verbal and therefore is difficult or foreign to most rural people. This characteristic typifies the majority of the village population.

2. Data Coding and Analysis

Coding the data from the pilot study has been a large job and has been in progress for over a month. Much scoring and coding must be done by hand, a necessity dictated by the explanatory nature of the data. Two to four people have been continuously at work on the data since July 23. Although much of the coding can be programmed into the final interview form for 1969, there will still be a need for hand scoring on two of the psychological scales used.

The analyses of data will be carried out at the University of Ottawa. A programmer* has been hired to do the programming which is now in progress. The programs to be used are largely available in Veldman (23).

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* Mr. Rosen, Applications Manager

3. Research Assistant in Ottawa

After the field work was completed, a full time research assistant joined the project.* He joined the staff on July 23.

4. Bibliographies

Bibliographies are now available which are pertinent to the study. The literature consulted during the summer has been compiled (11) in "Bibliography (References consulted summer, 1968)". In addition a bibliography has been acquired from the Charlottetown Library (PEI) on the population and historical background of the Island.

5. Sampling Procedure of the Study Proper (1969)

A final sampling procedure for the total Island has been devised and carried out. It is an adaptation of "sampling within a fixed radius of randomly selected points" (7). Aerial maps of the Island (scale - 1: 50,000 inches) were acquired from the Department of Energy, Mines and Resources, Ottawa. The mercator grids were numbered and approximately 5000 selected randomly. These yield approximately 10,000 people or 2,500 dwellings, the size of the initial sample required for next year's study.

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* Mr. Douglas Tate

## The Present Status of the Project: September 1

Much has been accomplished this summer, but a great deal remains to be done. Most of the methodological issues surrounding the study have been solved. An instrument has been constructed, a sampling procedure devised and the manner in which interviews must be conducted in Prince Edward Island to yield successful data is known. Some problems have not been resolved, but the necessary data and information are now in hand in order to arrive at solutions. For example, final decisions upon the scales to be included in the interview form await item-test statistics and data analysis.

A sizeable amount of data have been gathered in the villages which will yield valuable results in content as well as in statistical information.

The research psychologist returned to Vancouver August 24, though she will continue to work on the project there. The research assistant will continue full time on the project in Ottawa. Communications will be by mail or, if necessary, by phone.

The project thus far has been an exciting one. Many people have given time and effort to it. Some have been paid but even more have donated their thought and energies simply because they were asked or because they felt it worthwhile. For example, over 600 Island villagers

spent one to two hours each, being tested and interviewed. Village officials co-operated in discussions, giving advice and even being tested themselves. Dr. Beck arranged the introduction to the villages, acted as a consultant on initial design and plans, and arranged an office for the research team in Summerside during the period of the field work. Mr. McDonald in Ottawa and several Ottawa families with retarded children gave freely of their time to help the project.

## THE FUTURE

1. The Research Design

   There are two major purposes of the study which justify the preceding efforts: the Research Design and the Pilot Study Report. First and foremost is the Research Design, which will fully outline the proposed project in 1969 and request the funds with which to carry it out.

2. The Pilot Study Report

   The data from the pilot project are to be fully analyzed, interpreted and reported as they will yield not only information to be built into the Research Design, but also information which can stand as important in its own right. For example, what is the level of intellectual functioning in the villages? How does the village social structure deal with and handle cases of mental maladjustment, and especially mental retardation? Do an Irish Catholic and an Acadian village differ in the way retardates are managed? These are only a few of the questions

to be asked and answered.

Leading to the achievement of these two major goals are the following additional steps:

3. Completion of Data Analysis

   The bulk of the data analysis will be done in September. Much of the analysis is necessary before final decisions are made on instruments for inclusion in the final design.

4. Interpretation of Data

   The results of the analyses must be interpreted and conclusions drawn. In addition, the best combination of scores, for a retardation index must be determined.

5. Review of Literature

   Another Research Assistant will be hired to continue the compilation of critical summaries of mental retardation literature and summaries of background literature on Prince Edward Island, as well as to assist in data analysis.* The present research assistant will review Psychological Abstracts and summarize studies falling into the discipline of experimental psychology.

6. Development of Field Research Schedule

   The development of the final field research schedule involves (1) the selection of scales to be included and (2) coding procedures to minimize hand scoring.

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* Mr. Wayne Brighton joined the Project staff on September 16, 1968.

7. Field Manual

Work may be begun on a field manual at any time to be completed after the final Research Design is arrived at. It will document the instructions and information needed for the successful field performance of an interviewer.

8. Articles, publications and reports

A series of publications are planned in connection with the study proper and the pilot project. Discussions have already been held with journal editors on potential reports from the pilot study.

It should again be noted that the above items are, in fact, subordinate to or directed towards the preparation and submission of the major Research Design, which has been the overall purpose of the foregoing efforts.

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